



Canberra Region Kidney Support Group

Kidney News

The views expressed in this newsletter are not necessarily those of the CRKSG

THE BIG DONOR SHOW

MAY 2007, EUROPE, NETHERLANDS

The subject of organ donation received some of its heaviest publicity in Europe following the June 1st 2007 airing of 'The Big Donor Show' on Netherlands TV. Three patients on the show competed to receive a donated kidney. The show turned out to be a fake intended to highlight a shortage of donated organs.

In the month before the show, an important development occurred in the subject of organ donation. The European Commission's Directorate-General for Health and Consumer Protection (DG SANCO) published a report on a study it had commissioned in 2006. The study examines the attitudes of Europeans towards organ donation.

One of the questions considered by the DG SANCO study was whether Europeans have discussed the subject within their family circle. The study found that 41% of Europeans have talked about organ donation with family members. This percentage was slightly down on an equivalent figure of 46% in a 2002 study—the cause being that organ donation appears to be a topic less-readily mentioned by families living in the EU's 10 newest Member States.

Other aspects of organ donation looked at in the May 2007 DG SANCO study include: willingness to donate an organ after death; readiness to agree to donate an organ from a deceased close family member; and opinions about organ donation cards (and their use by European citizens).

European Commission Special Eurobarometer 272, *Europeans and Organ Donation: Report*, May 2007, PDF, 43 pages.

[http://ec.europa.eu/health/ph_threats/human_substance/documents/ebs272d_en.pdf]

(Courtesy of Health and Social Campaigners ' Network International)

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ANNUAL GENERAL MEETING

The annual general meeting of the Group will be held on Sunday 19th August 2007 at 2:00pm in Building 1, Room 22, Pearce Centre, Collett Place, Pearce . We need as many as possible to attend this meeting. In fact we are pleading with you to attend.

There is no need for you to nominate for committee positions if you do not wish to, however we do need people with ideas on fund raising and are perhaps willing to give some time to this pursuit. We are also need people with contacts in industry and other sources of sponsorship.

KIDNEY DISEASE DOUBLES

KIDNEY disease has quietly become Australia's “silent killer”, with a new victim dying every 35 minutes.

Latest figures reveal the death toll from kidney failure has doubled over the past 20 years and now surpasses breast cancer, road accidents, suicide and diabetes.

Experts say up to two million Australians are in the early stages of kidney disease without realising it and a third of the population is at risk. While survival of most chronic illnesses is improving, kidney disease is worsening and the national health bill for dialysis is rising by \$1 million a week.

Health professionals will today make a desperate plea to the federal Government for a national strategy to tackle the disease, which often shows no symptoms until it is too late.

Despite accounting for 12 per cent of all deaths - or 41 people a day, according to Australian Bureau of Statistics - it is not classified as a national health priority. In a letter to all federal MPs, Kidney Health Australia CEO Anne Wilson said there was “not one government dollar” spent on prevention, early detection or raising awareness.

She told The Sunday Telegraph that GPs and the public alike needed to be educated to improve detection of kidney disease. “It's a silent killer”, she said. “It's as insidious as cancer - it just creeps up on you and the next thing you know you are on dialysis or you are dead before you can go on it. There are all these people walking around with it. They could have done something about it if they just got diagnosed earlier”.

The 2007 national health bill for dialysis treatment is expected to be about \$600 million but is forecast to blow out to \$900 million by 2010, according to a financial report by the George Institute of International Health.

General awareness of kidney disease is low, as there are no public-health campaigns and symptoms often don't appear until the last minute. It often occurs alongside other lifestyle-related illnesses, such as heart disease and diabetes. Health Minister Tony Abbott launched a No Warning Signs public-awareness campaign in Canberra to coincide with Kidney Health Week.

The foregoing is taken from an article that appeared in the Daily Telegraph on 27 May 2007. The article was by Clair Weaver.



The Health Minister, Tony Abbott launching the No Warning Signs public-awareness campaign.



Kidney Health Australia CEO, Anne Wilson at the launch.

CRKSG Projects

The Group is in the process of financing another plumbing installation in the home of a disadvantaged kidney patient. If you need assistance with plumbing for home dialysis, purchase of various mobility and comfort aids, etc., then contact the Renal Social Worker who will assist the Group in assessing the level of assistance we can give.

Calendar of Events

Support Group Meetings.

When: The Second Tuesday of each month.
13th February, 12th March, 10th April,
8th May, 12th June, 10th July and 14th August.
AGM 19th August 2007 2:00pm

Where: The Pearce Community Centre
Building 1, Collett Place
Pearce ACT 2607.

When: 7:30 pm.
All welcome

Help

The CRKSG needs members to:

Lobby or participate as Patient Representatives, contribute to the newsletter, and act as patient support .

The CRKSG can provide the infrastructure that can support anyone with bright ideas that further the aims of the group. We are desperately in need of people with ideas!

You do NOT need to be suffering a kidney related illness to participate!

If we cannot get people to help, the Group will not have the means to assist those in need, or at worst, is in danger of folding.

KEEP YOUR EZIPARK PASS!!!

Now that pay parking has been discontinued at Canberra Hospital and Calvary Hospital, dialysis patients still have unlimited parking privileges. Display your EZIPark pass and you can park in 2 hour parking zones for unlimited time. Unless you have a disabled parking permit, don't park in the disabled parking bays.

New parking permits will eventually be issued to renal patients to replace the EZIPark pay parking cards. Meanwhile display your EZIPark card when you park to avoid getting a fine. If you have been fined for overstaying in a 2 hour parking zone, you can probably have the fine waived. Contact the renal administrative staff for assistance.

Additionally, readers may have noticed the work going on in the corner of Hindmarsh and Yamba Drives, opposite the Canberra hospital in Philip. According to the Canberra Times this is for the new ground level hospital car park which will be finished early September, weather permitting. The car park will have 562 spaces, mainly for hospital staff.

This ground level park is in addition to a new multi-storey car park planned for the hospital. It will be built over the next two years and will have 1400 spaces for staff and visitors. The car park is expected to be finished by June 2009.

CHRONIC KIDNEY DISEASE SUMMIT (CKD)

A one-day "International CKD Summit" is being organised by Kidney Health Australia and New Zealand Society of Nephrology to be held in Sydney on the 27th July 2007. Attendance at the summit is by invitation and will address the progress made in engaging Government on CKD issues, its early detection, best care protocols and re-sourcing in the U.S. and the U.K. and contrast this with any progress that has been made with Government in Australia.

The speakers at the summit will consist of an eminent list of International and Australian experts who have been invited to speak at this meeting.

Further detail may be found on the CRKSG website at — <http://www.crksg.org.au/>.

TRANSPLANT GAMES

The 2008 Australian Transplant Games will be in Belmont, Perth, Western Australia, during the school holidays from 4-11 October 2008. The local organising committee is well along the way in getting things organised.

The NSW and ACT branches of Transplant Australia want to have a good turnout to give both their best chance of winning the Victor Chang and Donor Family Shields.

The 2009 World Transplant Games will be held on the Gold Coast on August 22-31, 2009. Organisation of this event is well advanced. Last month (June) Gary Green and Olivier Coustere from the World Transplant Games Federation visited Australia to check on the preparations for this event. Transplant Australia are hoping for the largest ever attendance at a World Games.

If you are interested in participating or attending any Transplant Games, further information may be obtained from Nick Farley on mobile 0407 040 817 or email orgdonor@bigpond.net.au and from the Transplant Australia website at — <http://www.transplant.org.au>.

Readers should note:

- To participate in these games (national or world), the participant must be a financial member of Transplant Australia. (This is for liability insurance among other reasons). Membership forms can be downloaded from the Transplant Australia website.
- The Australian team is authorised by the Federal Government to represent Australia and to bear the coat of arms on the Australian team uniform.
- Selection in the Australian team for World Games is not automatic, as the person must qualify. Usually selection in the National team is based on performance in National Transplant Games, but there are other possible methods - contact the NSW/ACT executive committee for details.
- Those eligible to compete in the games are those who have had, or are waiting for an organ or tissue transplant, or are on dialysis.
- Supporters, living donors and family members of deceased donors are also welcome to attend.
- The standards at the National Games are highly variable, and we encourage and support all participants regardless of their level or expertise or athleticism.

[The foregoing was predominantly supplied by Transplant Australia (NSW/ACT).]

THE 16TH WORLD TRANSPLANT GAMES

The 16th World Transplant Games will be held in Bangkok, Thailand from 25th August – 2nd September 2007.

This year's event is expected to attract almost 2000 competitors from 40 countries.

The Transplant Games are open to financial members of Transplant Australia and provide an excellent opportunity to meet and compete with fellow transplant recipients in a range of sporting and recreational activities.

Events include golf, tennis, archery, cycling (road racing and time trials), petanque, badminton, volleyball, swimming, 10 pin bowling, squash, table tennis and athletics (track and field).

The fifty strong Australian team will include four Canberrans; Bone Marrow transplant recipients, Rob Benson and Steve Hall, Mick Kennedy (Double Lung) and Nick Farley (Kidney).

Further information may be found at the Transplant Australia and at the [16th World Transplant Games](#) websites.

SOME PHOTOS FROM LAST YEAR'S NATIONAL TRANSPLANT GAMES



Opening parade—some of the ACT Team at the National Transplant Games, Geelong 2006.
L to R: Rob Benson, Ivan Stibohar, Steve Hall and Nick Farley



The ACT Team wins the Donor Family Shield. The Shield is on display in the Organ Donor Coordinator's Office at TCH.
L to R: Ivan Stibohar, Rob Benson, Russell McGowan, Nick Farley and Steve Hall

IRON MAN

Shad Ireland the first dialysis patient to compete in and complete an Ironman© Triathlon in July 2004 at Lake Placid, NY is back to inspire other chronically ill patients and healthy people in general. An Ironman© consists of a 2.4 mile swim, 112 mile bike ride, and a 26.2 mile run which needs to be completed consecutively.

Of late he has developed and launched The Shad Ireland Foundation, a non-profit organization dedicated to showing kidney dialysis patients the importance of fitness to their well being, and how it can contribute to giving them a more "normal" life. Funds raised will be used to create fitness grants for those dialysis patients who need assistance to become more physically active. Shad states "I believe that physical fitness and exercise is the key which will unlock the door that provides a better quality of life for dialysis patients and those who suffer from chronic illness."

Shad was diagnosed with Kidney Disease at the age of 10 and has had two unsuccessful kidney transplants. He is now 34 years old and remains on dialysis three times a week for four hours per day.

See the whole story at <http://www.ironshad.com/>. More about the Shad Ireland and his Foundation can be found throughout the site.

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MEMBERSHIP APPLICATION/RENEWAL

Canberra Region Kidney Support Group Inc
PO Box 5051 GARRAN ACT 2605.
ABN: 77 396 063 641

Last Name: **First Name:**

Address:.....

Email:

Phone No:

I would like to make a voluntary donation to CRKSG for the amount of: \$..... Membership is free. All donations \$2 or more are tax deductible. Cheque/Money Order payable to CRKSG Inc. Please accept this application for membership of the Canberra Region Kidney Support Group Inc.

Signature: **Date:**.....

Post Form to:

The Treasurer
Canberra Region Kidney Support Group Inc
PO Box 5051
GARRAN ACT 2605.

NOTE: This form may also be used to notify a change of address/contact details.